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Report of the Washington Group on Disability Statistics

Note by the Secretary-General

In accordance with the request of the Statistical Commission at its thirty-seventh session,[1] the Secretary-General has the honour to transmit to the Commission the report of the Washington Group on Disability Statistics. The report presents the work completed by the Washington Group as well as its workplan for 2007. The Commission is requested to comment on the findings and conclusions of the Washington Group and the proposals for its future work. In particular, the Group is seeking the Commission's approval on its workplan for 2007, included in chapter III of the report.

* E/CN.3/2007/1.
[1] See *Official Records of the Economic and Social Council, 2006, Supplement No. 4* (E/2006/24), chap. I.B.

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Contents

		Paragraphs	*Page*
I.	Introduction	1–2	3
II.	Progress report on work completed	3–10	3
	A. Meetings and collaborations	3–4	3
	B. Recent activities and major achievements	5–10	4
III.	Workplan for 2007	11–12	5
IV.	Action to be taken by the Commission	13	6
Annexes			
I.	Membership of the Washington Group on Disability Statistics		7
II.	The short question set of the Washington Group on Disability Statistics, its rationale and context		8

Report of the Washington Group on Disability Statistics

I. Introduction

1. In June 2001, the International Seminar on Measurement of Disability recommended that principles and standard forms for indicators of disability be developed for use in censuses. There was a broad consensus on the need for population-based measures of disability for country use and for international comparisons. This work was greatly needed because data on disability, especially in developing countries, were scarce and often of poor quality. Furthermore, international comparability was often lacking, even among developed countries. As a result, the Washington Group on Disability Statistics was formed to address that urgent need.

2. The main purpose of the Washington Group is, therefore, the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability that is comparable throughout the world. More specifically, the Group aims to guide the development of a short set or sets of disability measures, suitable for use in censuses, sample-based national surveys or other statistical formats, for the primary purpose of informing policy on equalization of opportunities. A second priority is to recommend one or more extended sets of survey items to measure disability, or guidelines for such items, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items are intended to be related to the short set or sets of disability measures. The World Health Organization (WHO) International Classification of Functioning, Disability and Health has been accepted as the basic framework for the development of the sets. All disability measures recommended by the Group, short or extended, will be accompanied by descriptions of their technical properties and methodological guidance will be given on their implementation and their applicability to all population subgroups. The Washington Group disseminates its work products globally through the World Wide Web (http://www.cdc.gov/nchs/citygroup.htm) and scientific publications.

II. Progress report on work completed

A. Meetings and collaborations

3. The Washington Group has held six annual meetings since its inception: (a) from 18 to 20 February 2002 in Washington, D.C.; (b) on 9 and 10 January 2003 in Ottawa; (c) on 19 and 20 February 2004 in Brussels; (d) from 29 September to 1 October 2004 in Bangkok; (e) from 21 to 23 September 2005 in Rio de Janeiro, Brazil; and (f) from 10 to 13 October 2006 in Kampala. Annual meetings are rotated through major geographical regions to facilitate participation. In addition, two regional workshops were held in 2005 to provide technical assistance and training in pretesting the proposed census questions.

4. The Washington Group has sought to foster international collaboration and, in particular, to ensure that the efforts of the Group are broad-based and inclusive of voices from developing countries of every region of the world. Thus, representatives

of national statistical authorities, of organizations representing persons with disabilities and of other international organizations participate in the Group. Since its inception, the national statistical offices in 88 countries have appointed representatives to participate in it. Representatives of 66 countries have attended at least one annual meeting and 35 countries have attended more than one. Representatives of 79 national statistical offices are currently members of the Washington Group, as well as seven international organizations, six organizations that represent persons with disabilities, the Statistics Division of the Secretariat and other United Nations entities (see annex I).

B. Recent activities and major achievements

5. Since 2001, the Washington Group has: (a) developed a short question set, accompanying rationale and test implementation protocols; (b) provided training to countries in conducting its tests and, more generally, in disability data collection methods; (c) conducted standardized Washington Group tests in 15 countries; (d) analysed test results; and (e) endorsed the short question set (with minor revisions; see annex II).

1. Regional workshops

6. The Washington Group held two regional workshops in 2005, in Africa and Latin America, respectively. The workshops were directed primarily towards countries in the region concerned that were interested in including disability questions in their national censuses. The workshops familiarized countries with the Washington Group short questions set on disability, the accompanying rationale and procedures for testing the questions, and helped to build capacity in collection of data on disability in many developing countries. In addition to receiving training in conducting the tests of the Washington Group questions, those countries are working internally to improve their overall approaches to collection of data on disability.

2. Cognitive and field testing of the census questions

7. Protocols for administering tests of the Washington Group questions were developed by the Group and standardized testing was undertaken in 15 countries, including 13 where the testing was funded through a grant from the World Bank. The purpose of the testing was to ensure the validity of the questions and to better understand how they operated in different settings and cultures. The tests, as well as studies in other countries following the Washington Group approach, show an improvement over traditional census questions. Developing countries that had previously reported disability rates of about 1 or 2 per cent found rates between 8 and 15 per cent when using the Washington Group questions. Such rates are much more in line with data from developed countries that use more complex approaches to collection of data on disability.

3. Provision of technical assistance

8. The Washington Group used the World Bank grant to fund countries to conduct the tests and also to employ a consultant from January to June 2006 to provide technical training and to assist national statistics offices engaged in test activities. In-person technical support was provided to two national statistics offices in Africa.

Assistance via phone and electronic mail (e-mail) was provided to countries in Africa and Latin America as well as to India, the Philippines and Viet Nam.

4. Fostering international cooperation

9. The Washington Group has worked with the Statistics Division of the Secretariat, the Economic Commission for Europe, the Economic and Social Commission for Asia and the Pacific (ESCAP), the Economic and Social Commission for Western Asia, the International Labour Organization, WHO, the World Bank, the Budapest Initiative, the Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (SINTEF), the Inter-American Development Bank, the Organization for Economic Cooperation and Development, the Statistical Office of the European Communities, and others to promote a unified approach to disability measurement. Several World Bank data instruments have been heavily influenced by the work of the Washington Group (in India and Uzbekistan) and SINTEF has been working in Africa to conduct independent tests of the Group's questions. In addition, ESCAP and WHO, in partnership with the Australian Bureau of Statistics, conducted pilot studies on the Washington Group short set of questions and the longer WHO set of questions. The study results were presented and discussed during the fifth and sixth meetings of the Washington Group. The Group has also been informed that the question set has been pretested or added to surveys in at least 11 countries.

5. Endorsement of a set of census questions on disability

10. At the sixth annual meeting of the Washington Group, held in Kampala in October 2006, test results were reported and the short set of questions on disability (see annex II) was endorsed by the representatives of the 23 countries and five international agencies in attendance. Some minor modifications of the wording were suggested, based on pretest results presented at the meeting. The set comprises questions on six core functional domains: seeing, hearing, walking, cognition, self-care and communication. In countries where resources do not permit inclusion of six questions on a census, the first four domains are recommended for inclusion (seeing, hearing, walking and cognition); the Washington Group strongly endorses the use of all six questions, however. The questions were based on the model of disability inherent in the International Classification of Functioning, Disability and Health, with particular emphasis on international comparability.

III. Workplan for 2007

11. At its sixth meeting, the Washington Group agreed on a workplan for 2007. The plan delegates specific responsibilities to working groups that meet throughout the year (via e-mail and telephone conferences). The next steps for the working groups include:

(a) Work on the short set of questions for censuses, which comprises:

(i) Consideration of additional revisions to the short question set and the use of the short set as a screener;

(ii) Continuation of analyses of test data, including joint analyses with ESCAP and WHO;

(iii) Publication of test results from the Washington Group, ESCAP and WHO and country tests;

(b) Work on the extended sets of questions for surveys, which includes creation of a position paper outlining the plan and approach (blueprint) for developing the extended set, including the purpose, rationale and justification for the extended set as well as the issue of international comparability. Questions will be developed within the existing domains and new domains will be added to more completely assess equalization of opportunities. For example, a question on the use of mobility devices might be included to expand the domain captured by the question "Do you have difficulty walking or climbing steps?". Questions on psychological functioning might be added, for instance, to capture a domain that is not now directly represented in the short question set;

(c) Work on methodological issues, which entails:

(i) Evaluating proxy data (working group priority);

(ii) Determining how the questions work for specific sub-populations, such as children, and determining the age at which the questions are meaningful by evaluating the test data from children;

(iii) Determining the portability of questions across administrative modes.

12. The seventh meeting of the Washington Group will be held in Dublin from 19 to 21 September 2007. The objectives of the meeting will be to present:

(a) The additional work on the short set:

(i) Newly available results (if any);

(ii) The results of additional analyses by the Washington Group and ESCAP and country test data;

(iii) Any revisions to the original six questions;

(iv) Work on the use of the short set as a screener;

(v) Options for measuring upper body function;

(b) Proposals for an extended set and test results, if available. The Washington Group will collaborate with ESCAP, which has included development of extended sets in its 2007-2008 work programme, to build on the outputs of the current project. The working group will present a position paper, which will include the plan for, purpose of, and approach to developing the extended set specifically to assess equalization of opportunities;

(c) Discuss strategic issues.

IV. Action to be taken by the Commission

13. The Commission may wish:

(a) To express its views on the findings and conclusions of the Washington Group on Disability Statistics (see chapter II above and annex II);

(b) To consider and approve the draft workplan of the Washington Group for 2007, as described in chapter III above.

Annex I

Membership of the Washington Group on Disability Statistics

1. At present the national statistical authorities sending representatives to participate in the Washington Group include those of 79 countries and territories: Albania, Argentina, Armenia, Australia, Austria, Barbados, Belgium, Bermuda, Bolivia, Brazil, Cambodia, Canada, Chile, China, Hong Kong Special Administrative Region of China, Macao Special Administrative Region of China, Colombia, Côte d'Ivoire, Cuba, Czech Republic, Democratic Republic of the Congo, Denmark, Egypt, Finland, France, Gambia, Ghana, Greece, Guatemala, Hungary, India, Iran (Islamic Republic of), Iraq, Ireland, Israel, Italy, Japan, Jordan, Kenya, Latvia, Lebanon, Lesotho, Lithuania, Malawi, Mauritius, Mexico, Micronesia (Federated States of), Mongolia, Netherlands, New Zealand, Norway, Palestine, Panama, Paraguay, Peru, Philippines, Poland, Romania, Saint Lucia, Serbia, Sierra Leone, Slovenia, South Africa, Spain, Sweden, Syrian Arab Republic, Thailand, Tonga, Trinidad and Tobago, Turkey, Uganda, United Kingdom of Great Britain and Northern Ireland, United Republic of Tanzania, United States of America, Uruguay, Venezuela (Bolivarian Republic of), Viet Nam, Zambia and Zimbabwe. In the past, the Bahamas, Bulgaria, the Comoros, Costa Rica, the Dominican Republic, Ecuador, Estonia, Nigeria, Slovakia, Tunisia and the Turks and Caicos Islands have also participated.

2. Past and present representatives of international organizations representing persons with disabilities include the African Rehabilitation Institute, the European Disability Forum, the Inter-American Institute on Disability, the International Federation for Hydrocephalus and Spina Bifida and Rehabilitation International. Past and present representatives of national organizations representing persons with disabilities include the Association for Persons with Cerebral Palsy (Mexico), the Coordination Office for the Integration of Disabled Persons (CORDE, Brazil), the Disabled Organization for Legal Affairs and Social Economic Development (United Republic of Tanzania), the National Disability Authority (Ireland), the National Institute on Disability and Rehabilitation Research (United States of America), the National Union of Disabled Persons (Uganda), the Office of the Ombudsman for People with Disabilities (Puerto Rico), the Puerto Rico Council on Developmental Disabilities, and the National Secretariat for Social Integration of the Disabled (SENADIS, Panama).

3. Other international organizations that have previously or currently participated in the Washington Group include the Statistics Division of the Secretariat, the Economic Commission for Europe, the Economic and Social Commission for Asia and the Pacific, the Economic and Social Commission for Western Asia, the International Labour Organization, WHO, the WHO Collaborating Center for the Family of International Classifications, the World Bank, the Inter-American Development Bank, the International Development Project, the Organization for Economic Cooperation and Development, Partnership Health of the European Union, and the Statistical Office of the European Communities.

Annex II

The short question set of the Washington Group on Disability Statistics, its rationale and context

A. The short question set of the Washington Group

Introductory phrase

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

Core questions

1. Do you have difficulty seeing, even if wearing glasses?
   a. No — no difficulty
   b. Yes — some difficulty
   c. Yes — a lot of difficulty
   d. Cannot do at all
2. Do you have difficulty hearing, even if using a hearing aid?
   a. No — no difficulty
   b. Yes — some difficulty
   c. Yes — a lot of difficulty
   d. Cannot do at all
3. Do you have difficulty walking or climbing steps?
   a. No — no difficulty
   b. Yes — some difficulty
   c. Yes — a lot of difficulty
   d. Cannot do at all
4. Do you have difficulty remembering or concentrating?
   a. No — no difficulty
   b. Yes — some difficulty
   c. Yes — a lot of difficulty
   d. Cannot do at all

Additional questions:

5. Do you have difficulty (with self-care such as) washing all over or dressing?
   a. No — no difficulty

b. Yes — some difficulty

c. Yes — a lot of difficulty

d. Cannot do at all

6. Because of a physical, mental or emotional health condition, do you have difficulty communicating (for example, understanding others or others understanding you)?

a. No — no difficulty

b. Yes — some difficulty

c. Yes — a lot of difficulty

d. Cannot do at all

B. Statement of rationale for the short question set

1. "Disability" is an umbrella term that generally refers to the negative aspects of functioning, such as impairments, activity limitations or participation restrictions. While it is important to collect information on all aspects of the disablement process, it is not possible to do so in censuses. However, important information on selected aspects of disability can be obtained from censuses.

2. In their ongoing deliberations, the Washington Group has agreed that measurement of disability is associated with a variety of purposes, which relate to different dimensions of disability or different conceptual components of disability models. A fundamental agreement of the Group was the need for a clear link between the purpose of measurement and the operationalization of indicators of disability. Equalization of opportunities was agreed upon and selected as the purpose for the development of an internationally comparable short set of questions. This purpose was chosen because:

(a) It was relevant (of high importance across countries with respect to policy);

(b) It was feasible (it is possible to collect the proposed information using an internationally comparable short set of questions on censuses or surveys).

3. In order to address that purpose, questions were developed to identify persons who are at greater risk than the general population of experiencing restrictions in performing tasks (such as activities of daily living) or participating in roles (such as working). In particular, the goal was to gather information about limitations in basic activity functioning (i.e. functional activities such as walking, remembering, seeing, hearing). The "at risk" population captured by the short set of questions will include persons with limitations in basic activities who may or may not also experience limitations in more complex activities and/or restrictions in participation depending in some instances on whether or not they use assistive devices, have a supportive environment or have plentiful resources.

4. The questions were designed to provide comparable data cross-nationally for populations living in a great variety of cultures with varying economic resources. The objective was to identify persons with similar types and levels of limitation in

basic activity functioning regardless of nationality or culture. It was not our purpose to identify every person with a disability within every community.

5. The census format requires that a limited number of questions be devoted to any one statistic that needs to be produced. For reasons of simplicity, brevity and comparability, the choice was made to identify limitations in domains of basic activity functioning that are found universally, are most closely associated with social exclusion and occur most frequently. The information that results from the use of these questions is expected:

(a) To represent the majority of but not all persons with limitation in basic activity functioning in any one nation;

(b) To represent the most commonly occurring limitations in basic activity functioning within any country;

(c) To capture persons with similar problems across countries.

6. The proposed questions identify the population with functional limitations that have the potential to limit independent participation in society. The intended use of these data is to compare levels of participation in employment, education and family life for those with disability versus those without disability and to assess whether persons with disability have achieved social inclusion. In addition, the data can be used to monitor prevalence trends for persons with limitations in the specific basic activity domains.

7. The Washington Group recognizes that the short set of questions for censuses may not meet all the needs for disability statistics, nor will it replicate an evaluation of the population across a wider range of disability domains. A more comprehensive evaluation would be possible in other forms of data collection or in administrative data. The population captured by the short set will not represent the total population with limitations, nor will it necessarily represent the "true" population with disability, which would require measuring limitation in all domains and a much more extensive set of questions.

C. Context of the work of the Washington Group

8. The finalization of the short question set will facilitate the inclusion of the questions in the 2010 census round. The questions were developed according to the Fundamental Principles of Official Statistics[a] and are consistent with the International Classification of Functioning, Disability and Health. Most importantly, however, the endorsed questions support the draft convention of the rights of persons with disabilities recently finalized by the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities at its eighth session.[b] The short set addresses equalization of opportunities for persons with disabilities, which is one of the general principles listed in article 3 and the focus of

[a] See *Official Records of the Economic and Social Council, 1994, Supplement No. 9* (E/1994/29), chap. V, para. 59.

[b] A/AC.265/2006/4 and Add.1.

article 5 of the draft convention. It is also particularly relevant to the collection of data for policy purposes outlined in article 31 and will facilitate the monitoring of participation in cultural life, leisure, recreation, work and employment that is called for in articles 27 and 30.